

On the Move

News from the S.L.E. Lupus Foundation · Commemorating 35 Years of Caring for the Lupus Community

FALL 2005

“Get into the Loop” Hospital Tour Helps New Yorkers Learn About Lupus

The S.L.E. Lupus Foundation's one-of-a-kind patient education series looped through New York's five boroughs this fall, reaching out to the city's diverse communities with information on the chronic autoimmune disease, systemic lupus erythematosus (lupus). Hundreds of New Yorkers came out to hear specialists discuss topics from lupus kidney and heart disease to getting an accurate diagnosis, signing up for a clinical trial, and developing coping strategies. Social workers and patient advocates also took the stage at the tour's six events, which were presented in partnership with major New York area hospitals.

“In our 35 years working throughout the five boroughs, we have become the comprehensive and trusted lupus resource for people in the New York metropolitan area,” said Margaret G. Dowd, executive director of the S.L.E. Lupus Foundation. “Our programs have grown to be as diverse as the city we serve, educating and encouraging

early diagnosis and treatment.”

The first tour stop was at Manhattan's Hospital for Joint Diseases, where Jill Buyon, MD, discussed exciting new treatments and clinical trials being carried out to test them. She also touched on pregnancy considerations for people with lupus.

At the Jacobi Medical Center program in the Bronx, Meggan Mackay, MD, briefed participants on how lupus can affect the brain. As

much as 80 percent of people with the disease report headaches, confusion, fatigue, memory problems, or difficulty expressing their thoughts. Some have seizures or strokes. Bronx-born Saudia Sinclair shared details of her seven years of lupus-related mood swings, intermittent tremors, and depression.

At New York Hospital Medical Center of Queens, Gary Zagon, MD, provided an overview of diagnosing, treating and living with lupus. Foundation Director of Social Services, Enid Engelhard, CSW,



The free tour programs offered refreshments, giveaways (T-shirts, orange lupus awareness wristbands), and most importantly—information and support.

talked about coping with the disease and noted the many services offered by the Foundation, from one-on-one counseling to support groups, disease information, physician referrals, and emergency assistance grants. She described inner-city community outreach efforts and support centers provided by the Foundation's Lupus Cooperative of New York, which is currently in northern Manhattan and the Bronx. A new center is scheduled to open in Brooklyn in 2006.

At the fourth tour stop, Ellen Ginzler, MD, of SUNY-Downstate Medical Center in Brooklyn, provided an overview of lupus kidney disease, a serious complication in approximately 50 percent of people with lupus. Dr. Ginzler explained that in lupus, antibodies directed against one's own system can get deposited in the kidney and cause lasting damage. Severity of the condition varies, and if left untreated can sometimes result in kidney failure that requires dialysis or a kidney transplant. She also described exciting new treatments being developed and tested in clinical trials.

Mark Jarrett, MD, at Staten Island University Hospital, discussed musculoskeletal aspects of lupus, including joint and muscle pain at the tour's Staten Island event. In the final tour stop, Michael Lockshin, MD, of Manhattan's Hospital for Special Surgery, talked about the high risk of heart disease in people with lupus, with recent findings showing that women with lupus at as much as 50 times the risk for heart attack or angina (chest pain) than other women of the same age.

The Foundation thanks the participating hospitals for partnering in this well-deserved program, as well as the dedicated specialists who donated their time to share their valuable information and insights with lupus patients and families across the city's five boroughs.

This program was sponsored in part by an unrestricted educational grant from Genentech/Biogen Idec.



In Brooklyn, participants heard from patient advocates Robretta Magrae (l) and Candice Baptiste (c). Ellen Ginzler, MD (r), discussed lupus kidney disease.

Highlights of Camp Sunshine 2005

With the steadfast belief that all young people should have the chance to enjoy childhood to the fullest—especially those children who struggle daily with lupus—the S.L.E. Lupus Foundation proudly supports Camp Sunshine, a retreat for families dealing with life-threatening illnesses. Last summer, as a part of the **Let Kids Be Kids Fund**, the Foundation sponsored its largest group yet: 33 New York-area children with lupus and their families.

With its dedication to addressing the impact of illness on the entire family, Camp Sunshine is unique in the nation. One week each August, families of children with lupus come together at the beautiful Lake Sebago region in southern Maine to share a truly remarkable experience. The Camp's focus is on strengthening bonds and relationships within the family, as well as on bringing families together who are facing similar challenges. The program offers professional counseling, workshops, recreational opportunities, and an on-site physician. All of this is provided by the Camp and its sponsors at no cost to the families.



Letters from Camp

The Foundation received many wonderful letters from the campers and their families. Here are a few excerpts from their experiences at Camp Sunshine, Lupus Week 2005:

"Kenya was diagnosed with lupus approximately 2 ½ - 3 years ago...As a child she would go through periods of depression and low self-esteem and this illness only made matters worse....The day we arrived at Camp Sunshine her pressure and pulse rate became elevated. She felt light head-



ed so I took her to the doctor on site...she quickly got better when she realized all the concern on the part of the volunteers and other families. She didn't have to hide what she felt and everyone understood. At Camp Sunshine she can let her guard down. All her worries seem to fade away and she can be free to express her feelings whatever they may be."

"My son Benny was diagnosed in 2004 and it was a hard blow. But thanks to organizations such as this one we have been given the chance to learn more every day about this challenging condition. Camp Sunshine gave my family the opportunity to relax, to spend free time with each other. It gave my son the opportunity to make friends and open up a bit about himself. This family retreat has been the best ever."

"Nicole was diagnosed at age 11 and she is now 17. The Camp has helped her with the rough parts of her illness, and has been a very positive influence on her growth as a young woman with lupus. Now she wants to mentor other children. This was a life changing experience for her."

"Diana, Jessica and I truly appreciate this wonderful opportunity to spend a great week at Camp Sunshine. It has been a refreshing moment to see my daughter be able to do the activities that at one time she was unable to do...Camp Sunshine truly lives by its name, because when a family thinks that there may not be hope, there is this place where one finds hope and answers."

For more information on Camp Sunshine, visit www.LupusNY.org or contact Anita Cruso at the Foundation at 212-685-4118.



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